

NEW YORK RESOURCE GUIDE FOR CHILDREN WITH CEREBRAL PALSY AND THEIR FAMILIES



BROUGHT TO YOU BY



JAMES NEWMAN, P.C.
HELPING INJURED NEW YORKERS SINCE 1980

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HELP FOR YOUR CHILD WITH CEREBRAL PALSY

We all need a little help from time to time, and this is especially true for parents and caregivers of a child with cerebral palsy.

At James Newman, P.C., we are a family law firm with family values. Over the 40 years since we opened our doors we have helped hundreds of families navigate the legal process in the New York State Courts. Our attorneys will help to determine if you are eligible for financial compensation for your child's birth related injuries in order to help the costs that come with raising a child with cerebral palsy.



Call the father and sons team at James Newman, P.C. today at (718) 823-3122 so we can help.

In addition to legal counsel, our staff cares deeply about your family and finding the support they need. As members of our local community here in New York we work tirelessly to help our clients find the resources and assistance they need.

We created this free guide to help inform you of your options and help get you started if you or a loved one is living with a child with Cerebral Palsy.

LOCAL & NATIONAL COMMUNITY SUPPORT ORGANIZATIONS

Coping with a life-changing diagnosis like cerebral palsy can be difficult and isolating.

In our experience joining a support group is extremely beneficial for families, as these amazing organizations dedicate their time to providing physical, mental and financial support to families in need.



These communities bring together a vibrant community so that no parent feels alone in their journey raising a child with cerebral palsy. They also provide tips and advice from those who have already been through many of the same struggles of raising a child with cerebral palsy. By talking with members parents often feel more prepared for their family's future.

Cerebral palsy groups help families with:

- Relieving stress & offering a positive outlook
- Giving hope & understanding
- Finding reassurance
- Providing a platform to share their struggles and achievements

SUPPORT GROUPS AND ORGANIZATIONS

There are many options for support across the county. Both national and local support groups have been established with the goal of ensuring access to vital resources and providing emotional and medical support close to home.

The following organizations have affiliate programs in most major cities across the U.S. You can simply visit their websites to find a list of nearby affiliate groups that provide a multitude of services for both children and adults with cerebral palsy.

United Cerebral Palsy (UCP)

<https://www.ucp.org>

The mission of UCP is to educate, advocate, and provide support resources for individuals with disabilities. They aim to provide tools to be independent and lead a happy, healthy life. UCP also pushes for the social, legal, and technological changes that would make it easier for individuals with disabilities to achieve their dreams.



CP Daily Living

<http://cpdailyliving.com>

Managed by a mother of a child with cerebral palsy and epilepsy, this site is designed to give families and caregivers dealing with cerebral palsy a central place for practical information and resources within the context of an emotionally supportive community



CP Kids Coalition

<http://reachingforthestars.org>

This organization was founded by Reaching for the Stars. The coalition is a group of young people who produce articles and engage in discussions about the issues surrounding transitioning into adulthood



with cerebral palsy. This is a great place for young adults with cerebral palsy to meet other people they can relate to.

Cure CP

<http://curecp.org>

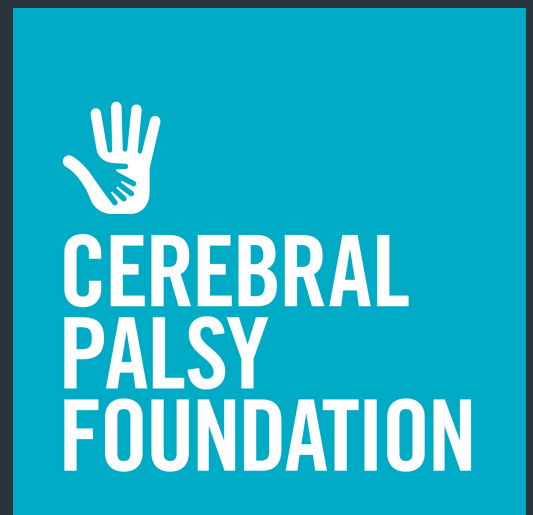
This organization was founded by two families that were directly affected by cerebral palsy. These parents created Cure CP to help fund and support research for cerebral palsy. Cure CP specifically supports research geared toward developing a cure and providing hope for the future



Cerebral Palsy Foundation

<http://yourcpf.org>

This organization contributes millions of dollars each year to cerebral palsy research. This research involves studies and clinical trials and focuses on finding new treatments that increase mobility and improve the overall quality of life for people with cerebral palsy. The Cerebral Palsy Foundation also campaigns to increase the level of federal support for people with cerebral palsy. They are leaders in advocating for better educational programs for doctors, nurses, and therapists



Cerebral Palsy Research Registry

<http://cprp.northwestern.edu>

Register your child into a secure database that is used to connect families with researchers studying cerebral palsy. A notification will be sent with studies that you qualify for, or you can opt to have researchers contact you directly. The choice to enroll in a particular study is entirely up to you and your family



Easter Seals

<http://easterseals.com>

Easter Seals is a nonprofit organization that

provides services for more than one million children and adults with autism and other disabilities, such as cerebral palsy. They provide support services for medical rehabilitation, residential services, job training, childcare, adult day programs, and camping/recreation.



Family Voices

<http://Familyvoices.org>

Family Voices promotes quality health care for children and youth with disabilities. They work closely with government leaders and medical professionals to ensure that individuals with disabilities have their voices heard



March of Dimes

<http://marchofdimes.org>

Their expansive support community provides a place to share stories through various online discussion boards and forums. They also have a large social network of parents who have experience raising a child with special needs. March of Dimes also connects their members with other parents located in the same part of the country. This is a great way to create a local support system that all parents can benefit from.



Parent to Parent USA

<http://p2pusa.org>

This non-profit organization provides emotional and informational support for families of children who have special needs. They match experienced, trained "Support Parents" with families in need. Their affiliate groups are typically started by parents of children with disabilities.



PARENT TO PARENT
USA

Reaching for The Stars

<http://reachingforthestars.org>

This advocacy group primarily strives to increase federal funding for cerebral palsy research. They focus on improving treatment methods used in children with cerebral palsy, and they work endlessly towards finding a cure.



Reaching For The Stars

The Arc

<http://thearc.org>

Founded in the 1950s by parents of children with an array of developmental disabilities, the Arc provides support for families and children with cerebral palsy across the nation. They offer more than 730 state and local chapters



ONLINE SUPPORT GROUPS



Special Needs Moms for Moms

<http://specialneedsmomsformoms.com>

This online community provides a vast social network for parents and families of children with special needs. Members are able to share information through an online forum. Parents in this group can offer

support, organize local meetups, and provide inspiration for other families



Mommies of Miracles

<http://mommiesofmiracles.com>

This is the world's largest online support organization for mothers of children with disabilities. Mommies of Miracles provides a network of resources, products, and services that help inspire and educate mothers. They match families to create a local support system.

SPECIAL EDUCATION

By law, schools must provide special help to eligible children with disabilities. If your child is eligible to receive special education services, a team of school professionals will meet with you to write an individualized education program (IEP) for your child.

Individuals with Disabilities Education Act (IDEA) Services

<http://sites.ed.gov/idea>

Early intervention and school-aged services are available through the Individuals with Disabilities Education Act (IDEA).

Part C of IDEA covers early intervention services (birth through 36 months). Part B applies to services for school aged children (3 through 21 years old)

Part C of IDEA: Early Intervention for Babies and Toddlers

Early intervention services can help children from birth through 36 months of age learn new skills, whether they have been identified recently with motor and movement delays or already have a cerebral palsy diagnosis. Early intervention services can start even before a diagnosis is made.



The first step is to have an Individual Family Service Plan (IFSP) developed by a team. This includes both parent and provider input. The IFSP describes the child's current level of development, family needs, specific services to be provided to the child and the family, and a plan to transition to public school.

Early intervention services may include

- Family training
- Counseling
- Home visits
- Occupational, physical, or speech therapy
- Hearing loss services
- Health and nutrition
- Social work
- Assistance with service coordination
- Assistive technology devices and services
- Transportation

Part B of IDEA: Services for School-Aged Children

Free services for school-aged children with developmental disabilities are provided through the public school system.

Before Part B services start, an Individualized Education Plan (IEP) is developed for children 3 through 21 years of age who qualify for special education services from school districts. An IEP is similar to an IFSP, but it is more focused on the child's goals rather than the family's goals.



Services covered under IDEA are

- Special education
- Physical, occupational, and speech therapy
- Supplementary aids and services
- Adaptive equipment
- Special communication systems

Center for Parent Information & Resources

<http://parentcenterhub.org>

This organization supports national Parents Centers who serve families of children with disabilities. You can locate a center near you on their site. The site also explains the IEP process in detail and offers information and materials for families about special education services

ADAPTIVE CLOTHING

There are lines of adaptive clothing specially-designed to fit wheelchairs, G/J tubes, diapers, and more. This can make a caregiver's life much easier and allow your child to be more comfortable. Some companies carry bodysuits in larger kid sizes, to keep hands away from medical equipment.

Koolway Sports

<http://koolwaysports.com>

Koolway Sports makes custom-made outerwear to fit a child's body frame and wheelchair configurations. Options include half-backs, full zippered sleeves, zippered hoods, hidden G/J tubes, and shoulder harness openings.



Ross Daniel Adaptive Apparel

<http://rdadaptiveapparel.com>

This company carries fashionable and comfortable adaptive socks and shirts to accommodate children who wear leg braces or ankle-foot orthotics.



Cat & Jack

<http://target.com/c/kids-adaptive-clothing/-/N-1laue>

Available through Target, this adaptive clothing comes with design features such as no-tag sensory-friendly, hidden opening for abdominal access, high-rise bottoms for diaper coverage, and more.



Shoes for AFOS

<http://shoesforafos.com>

Shoes for AFOS offers custom made shoes and boots to accommodate orthotics such as AFO, KAFO, DAFO, and SMO braces



PLAYGROUPS



Playgroups for children with physical and cognitive disabilities are a great option for children with cerebral palsy. Playgroups meet during various times throughout the year and are available in most major U.S. cities. Under specialized care, children with cerebral palsy can grow emotionally, mentally, and physically from friendships and independence

SUMMER CAMPS

Summer camps help to ensure that children with cerebral palsy are learning valuable social skills and independence.

Camps for children with cerebral palsy are equipped with accessible facilities and experienced staff. Children in camps participate in a number of activities, including swimming, hiking, fishing, crafts, sports, and campfires. By taking the focus off of their disability, children with cerebral palsy can form meaningful friendships and memories.

Some summer camps offer inclusive programs and activities to bring all kids together. This way, everyone can enjoy activities equally, and

nobody is left out of all the fun. Other camps are dedicated exclusively for individuals with one or more of a wide range of special needs



Very Special Camps

<http://veryspecialcamps.com/summer/cerebral-palsy-camps>

Locate a summer camp or program based upon your child's requirements and criteria in this directory of camps

MEDICAL TREATMENT

Treatment for cerebral palsy is multifaceted, often requiring multiple doctors and therapies. Early treatment usually has the greatest chance of improving a child's condition. The purpose of treatment for cerebral palsy is to promote the most normal, manageable, and healthy life possible.



American Academy for Cerebral Palsy and Developmental Medicine (AACPDM)

aacpdm.org/providers

The Academy is comprised of over 1,100 health professionals dedicated to education, research, and services for the benefit of people with cerebral palsy. Locate an AACPDM member by location, specialty, and/or patient type.

FINANCIAL RESOURCES

The cost of caring for a child with cerebral palsy over a lifetime is around \$1 Million, in addition to normal living expenses. This can be an overwhelming figure for families.



By finding a financial support organization that works with their child's individual needs, parents can feel more secure about their family's future. There are also government benefits available that can offset the costs of cerebral palsy treatment. By finding ways to manage the expenses associated with cerebral palsy, parents can ensure their child receives the therapy, medications, surgeries, and treatment they need to live a full life.

Children's Hemiplegia and Stroke Association (CHASA)

<http://chasa.org>

CHASA provides financial assistance and scholarships to families in

need. It is dedicated to helping parents of children with cerebral palsy by creating a network to share information about treatment clinics and educational programs.

UnitedHealthcare Children's Foundation (UHCCF)

<http://uhccf.org>

UHCCF provides families affected by cerebral palsy with the opportunity to receive access to health-related services that are not covered by their family's commercial health insurance plan. This group provides grants of up to \$5,000 annually per child, even to families without a UnitedHealthcare insurance plan.



MORGAN Project

<http://themorganproject.org>

The MORGAN Project is a non-profit organization established by Robert and Kristen Malfara in honor of their son Morgan, who suffers from a rare form of leukodystrophy. Their mission is to raise awareness, offer support for parents of children with special health care needs, and provide guidance, resources, and gently-used disability equipment.



GOVERNMENT BENEFITS

Federally Funded Government Programs:

There are five federally funded programs that offer additional income and insurance for those with cerebral palsy. These programs include:

1. Supplemental Security Income (SSI)
2. Social Security Disability Insurance (SSDI)
3. Medicaid
4. Individuals with Disabilities Education Act (IDEA)
5. Children's Health Insurance Program (CHIP)

While this funding originates within the national government, benefits are accessible through your state or city government. This makes it easier for parents to apply for and receive the help they need without having to endure a lengthy process of evaluation.

Local government agencies are responsible for dispersing the funds allotted to their citizens with disabilities. To apply for these government benefits or insurance plans, parents should seek out any necessary applications and forms through their local council

Supplemental Security Income (SSI) Benefits

<http://ssa.gov/benefits/ssi>

SSI is a monthly income for children and adults with serious disabilities, such as cerebral palsy. SSI is reserved for low-income families.



Social Security Disability Insurance (SSDI) Benefits

<http://ssa.gov/disability>

SSDI provides monthly income for adults that are unable to work due to their disabilities. SSDI does not require the applicant to have a certain income amount to receive benefits.



Medicaid Benefits

<http://medicaid.gov>

Medicaid is a federal health insurance program set up for families with limited income. Many families affected by cerebral palsy use Medicaid to help pay for medical expenses, housing, and assistive devices.

Medicaid.gov
Keeping America Healthy

Individuals with Disabilities Education Act (IDEA) Benefits

<http://sites.ed.gov/idea>

IDEA is a federal law that requires schools to serve the educational needs of students with special needs. Children with cerebral palsy are generally eligible for special education and treatment services provided by IDEA. This program offers services for individuals up to

Individuals with Disabilities
Education Act (IDEA)



21 years old. Also, children who are showing signs of cerebral palsy but haven't been officially diagnosed may still qualify for special education services. IDEA is meant to foster an environment that is more conducive to learning by providing access to an array of accommodation services

Children's Health Insurance Program (CHIP) Benefits

<http://healthcare.gov/medicaid-chip/childrens-health-insurance-program>

CHIP provides low-cost health care coverage to families that exceed the income requirement for Medicaid through both Medicaid and separate CHIP programs. CHIP coverage is offered in every U.S. state, and the costs associated with CHIP coverage differ for each family. However, this health insurance option ensures that you won't have to pay more than 5% of your family's income for the year



NEW YORK STATE MEDICAL INDEMNITY FUND

New York State Department of Health

https://www.health.ny.gov/regulations/medical_indemnity_fund/

The Medical Indemnity Fund (MIF) was established by Chapter 59 of the 2011 Session Laws of the State of New York. The MIF was designed to provide a funding source for future health care costs of "qualified plaintiffs," as defined by law, who suffered birth-related neurological injuries due to medical malpractice during a delivery admission.



LEGAL RESOURCES

Cerebral palsy can impact a child throughout their entire life. Oftentimes, children require therapies, surgeries, assistive devices, home modification, and more. Adults with cerebral palsy are likely to face many obstacles as they continue to manage their symptoms in adulthood.

If you have any reason to believe that your child's condition is the result of medical malpractice, begin the lawsuit process as soon as possible, as legal deadlines vary by state.

Your family may be entitled to receive valuable financial compensation that can be put towards alleviating the overwhelming cost of cerebral palsy treatment.



Contact the attorneys at James Newman, P.C. at (718) 823-3122 for a free legal case review. They will be able to help determine if you are eligible for financial compensation and guide you through the legal process.